



Derive

CCSIMO MARCO MAZZONI

a cura di

PER UNO STATUTO  
DEL CORPO

GIUFFRÈ EDITORE

# Per uno statuto del corpo

a cura di  
Cosimo Marco Mazzoni

Copertina: di A. BERARDI



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schiosa, come tutte le relazioni, ma anche fonte di grande piacere, conoscenza, intimità profonda. La fine della guerra tra i sessi, nella prospettiva di Atlan, richiederebbe allora un sacrificio e una rinuncia che, oltre ad essere, credo, del tutto insufficienti al compito, di nuovo le donne dovrebbero fare. Con il rischio assai concreto, oltre tutto, che decidere, invece, di avere una gravidanza non diventerebbe tanto una libera scelta, quanto qualcosa che alla fine alcune o molte delle donne cui sarebbe negato l'accesso all'utero artificiale dovrebbero ancora fare, e per questo sarebbero ancor di più ridotte e trattate come mere incubatrici.

#### *Riferimenti bibliografici.*

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JAMES RESTON JR.

#### THE DISABLED BODY

I am not a lawyer, though the story I will tell has many legal ramifications. I'm not a philosopher, though our personal circumstance has many philosophical implications. I'm not a biologist, though I have become deeply interested in bioethics. My part in this colloquium is to talk about the disabled body or the disabled person, to bring the discussion here down from the abstract to the concrete. I represent not the question of all humanity but of one single human being. How society deals with members of its family like my daughter is not a legal question or biological question only. I address the problem of disability as a father, as a writer, as a consumer of the technology that is now facing us very quickly.

I will look at this question of the disabled body from three perspectives: from the family, from the society, and from the standpoint of a writer who tries to make this different, « abnormal » person into a romantic figure of literature.

The fundamental question about the community of the disabled is whether it is embraced or whether it is excluded. This is relevant from the microcosm of the individual and from the macrocosm of the society. To include or to reject and shut away? To include or to separate? How a society deals with this challenge says something fundamental about what that society is. It defines a basic characteristic.

In the last sixty years there has been a fundamental shift in the attitude toward this community. The very low point in that attitude came in World War II when some 200,000 disabled per-

sons were exterminated. Just thirty years ago in the United States, this community was essentially viewed as non-human. Its members were non-persons. Slowly we have moved from a pattern of institutionalization to inclusion. There have been important laws passed that promoted this sense of inclusion.

Most importantly, the Americans with Disabilities Act which was passed in 1990 has done a tremendous amount to allow mobility and access of handicapped people to public buildings. In America immobile people get around everywhere in little carts. There are good services for the blind and deaf... Another important law, passed in 1975 is called the Individuals with Disabilities Education Law. It ensures equal rights to the disabled in education. These individuals, once shut away in separate schools, have been moved into regular schools. This is called « mainstreaming » and it has become the accepted policy all over our country. We now even have politically correct language when it comes to the disabled... We're not supposed to use the word handicapped any more. « Disabled » is the correct word. « Brain injured » is thought to be more benign than « mental retardation ».

But this community, whatever it is called, is still very dependent upon others, and upon society at large. We know from our own personal circumstance, that, notwithstanding these legislative strides forward, American society has a long way to go, particularly for disabled persons after they are 21 years of age. Our daughter happens to be 24. The area of « meaningful work » is a huge area for challenge, for us and for all families in our circumstance. How should the mind of a disabled person, especially a mentally retarded person, be stimulated? And how can they be socialized, with the wide range of friends that normal people enjoy?

We in America have included these persons to a large degree, but we still separate them. So we have a long way to go.

I have labored as a writer for 35 years, writing books of

many sorts: novels, plays, essays, journalism, and histories. But it has been a literary life with a difference. In 1983 my daughter, Hillary, my third child, became desperately ill when some sort of undefined, evil seed invaded her brain, destroyed her language, and gave her intractable brain seizures from which she still suffers today 22 years later. To this day, we do not know what happened to her. Many doctors who examined her are totally confounded about what exactly happened to her when she was first struck down at the age of 2 years. We watched this whole body change. The whole aspect of her became different before our very eyes. Medication bloated her body. She looked strange. She made strange sounds. She behaved in strange ways. She was in constant pain. Not only was she in chronic pain, but the people around her were also. It was a family life of frequent crisis and constant chaos.

Soon enough, we entered into the community of the handicapped and mentally retarded with trepidation. There is about that world a certain circus atmosphere. Just as you recoil from the misshapen bodies and strange behaviors of others — and there were many in that community that were in far worse shape than Hillary — you hope that others will not recoil from your own child. But as you recoil, you understand how others have great difficulty in confronting twisted bodies and injured brains and prefer to turn their heads away.

What happens with families who experience this is the following. The first phase is self-exclusion from society. Families recede. Through embarrassment or anger, they separate themselves without being separated. In our case, there was a long period of frustration, particularly because there was no diagnosis. And then as if that wasn't enough, her kidneys became implicated, probably through aggressive over-medication in an attempt to control the seizures. Now, a second major body function was shutting down. And this led eventually to kidney failure and eight years of dialysis. In those years we waited for the miracle of a kidney transplant, bedeviled by the reality that the

demand for organs far exceeds the supply. Doctors told us that there was hope, and pointed out, as if to comfort us, that just thirty years ago, doctors had to make choices about who would live and who would die.

The system of organ transplantation in the United States works as follows: the country is divided into separate regions. You go on a list. The list is called the « cadaveric » list, by which is meant that the person in need of an organ waits for just the right person, with just the right chemistry, to die. Therefore, in effect, you are waiting for just the right tragedy. And this can lead to macabre thoughts and black humor. The donor means the one who gets hit by a truck. In private, transplant doctors call motorcycles « donor mobiles. » There is another kind of list. That is called family donation. That describes a situation when a family member donates one of his two kidneys to another family member. The doctors like that situation. The chemistry is more exact; the « match » is better... In one room, a kidney is taken out, and it is moved across the hall to another room, where it is put in. Because doctors like this process for its more exact fit, families like ours come under significant pressures from their doctors to acquiesce in a « dedicated » donation.

We waited for eight, long, frustrating years for that transplant. As time went by, we watched our child dwindle. In the process I became very interested in alternatives: animal transplantation, stem cell « tissue » generation, even in the cloning controversy. We found ourselves constantly suspicious of doctors. We had been told that the wait would be only three years. We were listed on a handful of occasions as the « backup » recipient, but somehow the primary candidate always got the kidney. I became convinced that there was an asterisk next to Hillary's name on the list. Because she was handicapped, we suspected that the medical community did not want to « waste » a precious kidney on an individual already so flawed.

Six years into our wait, we shifted Hillary from the Maryland-Virginia list to the list in the state of Iowa in the American

Middle West. I had heard that the cases moved faster there. When Hillary was examined in Iowa, a doctor said to me, « Yes, we will take her on our list. It is the humane thing to do ». That was the first time I had heard a doctor use that term « humane ». That very humanity in Iowa, as opposed to the indifference of Virginia, seemed then, and seems to me now, to define Iowa as a very special place.

But then she was finally transplanted in Iowa in the summer of 2003. I still marvel at that science, that a critical organ can be moved from one human being to another and made to work. In our case, it has worked perfectly. But as the system now operates, the transplantation of human organs has a Janus face. Our joy was linked to other family's tragedy. Here, the victim was a beautiful young man, 18 years old, who was intelligent, and caring and athletic. He was killed in a race of so called « all terrain vehicles » at a county fair in Iowa. As his family grieved for him, we were being called in Washington. As we flew west in euphoria, his family was being forced to sign endless documents. Did they want to donate his eyes? What about his skin? His liver? His heart? They were being asked to approve a virtual butchering of his body. Their first reaction was: don't touch him! But in due course, they were persuaded by a doctor who said, « We can take him to the morgue right now, or we can make a stop along the way and save seven lives ».

Hillary's transplant in Iowa made it possible to write my book.

Why write such a book?

I realized early on in thinking about that question that one's own experience, no matter how intense it might be for oneself, is not necessarily intense for everyone. Will anyone else be interested, I asked myself. Why should they be interested? How can I interest them? I answered those questions for myself as follows. I am a writer who has devoted his life to writing books. I have

had a unique experience, and in that experience, we as a family have learned some rather profound lessons that might be useful for others.

Literature can make a difference. It can change attitudes. It can help others in same or similar circumstances who feel isolated and who are in need of wisdom. It can humanize medical crisis, which is often, for the layman, confusing and dehumanized. Rarely, at least in the United States, do doctors address the grief and depression and confusion of their patients. The easier path is to present a bewildering set of figures and labels.

In American letters, there is a discreet but growing body of literature by fine writers who are addressing profound misfortune in their own lives. The novelist, William Styron addressed his depression in a book called *Darkness Visible*. Joan Didion took on her grief at the death of her husband and her daughter, both in a book and a play. The Nobel Prize winning novelist from Japan, Kenzaburo Oe, wrote a beautiful novel called *A Personal Matter* that was inspired by the mental disability of his son. When we were experiencing the initial assault on Hillary's brain, and later on her kidney, we found that there was very little useful to read.

I was also inspired to write the book in the context of the war in Iraq. When so much in the news is about death and the splattering of body parts in combat or in the marketplace of common people, it seemed to me useful to return to the value of a single life, even if that life involved a misshapen body, the absence of speech, a chronically ill and strangely behaving individual.

*Fragile Innocence* is a tale of the heart. It is a story of love and loss, of coming to terms and hope. It pleases me that it has been received as a love story. But it is also a mystery story, for the book chronicles a search to discover what happened initially to Hillary. It is not a medical case study, for medical case studies separate rather than include the individual in the wider human experience. It is not a book about brain seizures or kidney

transplants, but about the family dynamics of dealing with chronic illness or constant emergency. There are many sad stories that are a lot sadder than ours. But I wanted to invite the reader to embrace Hillary, and to embrace and even gaze with joy and admiration upon a disabled person. I wanted to invite loving attention for my main character, rather than to create a disturbing portrait from whom the reader would recoil and avert his eyes.

To create a three-dimensional portrait of a character who can not talk is a major challenge for any writer. Dialogue and a description of feeling is central to the writer's craft. Moreover, I wanted not only a textured portrait, but a romantic figure as my central protagonist. We knew Hillary to be a tough customer. She was and is captivating, complicated, mysterious, and devilish. But in reaching for literature, it is not enough simply to say those things. The qualities must be demonstrated.

Balance is always important. If I included too much in the story, I might harm my own family. If I included too little, the story might be boring and not worth publishing or reading. There are other perils in writing an intimate memoir. There is the trap of making the story cloying, self-pitying, self promotional and self serving, as if the writer is encouraging the reader to say, « Aren't you wonderful. Aren't you noble ». That I wanted to avoid at all costs. Therefore, I needed to step back and try to look at my own story as objectively as I possibly could. To be literature the story must connect, not separate. The reader must feel a sense of identification with the central characters.

The reception of *Fragile Innocence*, when it was published in March 2006, was extraordinary. It was well and prominently reviewed, but more importantly, it brought out of the shadows many people who were suffering from some sort of chronic illness in their family. I came to realize that if you tell one story of one individual in misfortune, and tell it well, it can carry universal interest for many families, regardless of whether the details of the illness are similar. For an established writer to tell an honest

personal tale, can certify the stories of others. My story became a validation for theirs. It made me realize how many families with chronic illness suffer in silence.

Since I had written about our anger, isolation, confusion, and sometimes despair, it became okay for these families to talk about these same things in their experience. It was okay to confront doctors, okay to make mistakes — we all do. It was comforting for others to hear from me that the battles one fights in this situation seem endless. I also have received many letters. A typical example is the following:

Dear Mr. Reston

I just finished your book and was compelled to jump up and search out your address and write to you immediately. My 14 month old daughter Alice suffers from tuberous sclerosis complex, a condition which has resulted in a seizure disorder and dangerous kidney disease (which will eventually require transplantaion) with the near promise of developmental delay. So, to say that your story resonated with me would be a massive understatement. Of course, our story differs in that we had a diagnosis from the get go but there was still a letting go of the vision of who our Alice, our third child, was going to be.

I want to thank you because in the last 14 months I have had a crash course in hospitals, insurance, the limitations of compassion both of doctors and of my friends and family, and the morbid lengths that my imagination will go to when trying to cope, and I have luxuriated in love for Alice my final and entirely lovable baby. But I hadn't yet — until about 30 minutes ago — until I read that wonderful account of Hillary's 21st birthday — looked forward with joy to Alice's unfolding life.

You can't know and I'm not even sure I know yet the ways in which your book has helped me (and will help my husband and my 6 and 4 year old children.) Thank you a million times.

With Admiration,

In public appearances, I would be asked profound questions:

« How did the constant unrelenting tension and anxiety affect my marriage? »

« How did our situation affect our social life? Did friends desert you? »

« How did your healthy children handle the situation? »

« How did you cope with the early days of medical ignorance, when the doctors could not figure out what was wrong? »

« How should the culture change in its attitude toward the disabled? »

With all literature the author hopes his story will achieve the universal. Hillary's case personalizes some of the most profound bio-ethical questions of the future like stem cell research, animal transplantation, genetic therapy, even cloning. Of these stem cell research is the easiest to address. It is likely that in ten or fifteen years, the precious kidney that Hillary received from that tragic boy in Iowa will fail. What then? Will we have to go on another kidney transplant list? The clock therefore is ticking for us. Stem cell research offers the hope that organs can eventually be grown in a petri dish. If that should be the case, it would eliminate this terrible nexus between joy and tragedy that we experienced with the family in Iowa. Not only does stem cell research offer the hope of tissue generation, it also offers the hope of brain regeneration. Perhaps Hillary has come along too soon for these stem cell miracles, but politicians need to step aside and allow this science to proceed. Those who might be helped need to know if stem cell therapy is a real hope or a false hope.

Animal transplantation or xenographs is a harder ethical question for me. If it became possible to transplant immunologically-stripped pig kidneys into humans, what would I think about that? It raises the profound question of whether the human race becomes less human, if fundamental organs in the human body are routinely replaced with organs from other species. At present, this is an academic question, because science has not solved the retrovirus problem, that is, the creation of totally unknown diseases that could result when cross-specie transplants are attempted. But I believe science will solve this problem, and soon. Will we then have pig farms next to every major hospital

in the world? In the phrase of Aldous Huxley from his novel, *Brave New World*, there would be an « organ store in the sub-basement » of every hospital. To answer that question ethically, one must address an ultimate question: if your child is about to die, and the only thing that can save her is an animal organ, would you approve its implantation? Almost everyone would answer in the affirmative.

Hillary's case also personalizes the area of genetic manipulation. With the creation of the Human Genome Map, the hope arises that « misspellings » in the human genome of an ill person might be altered by « knocking out » the evil gene that has caused the disease. In families that are experiencing desperate illness, this can lead to wild dreams. Is it possible that the evil seed that stole Hillary's language might be identified, and in some way, altered or removed by genetic manipulation. If so, would she suddenly, magically begin to talk, and tell us all she has been going through in the past 22 years. I can well imagine that like her mother she would have a sharp tongue. Of course, this is only a dream. But the medicine of the future could easily focus on the predisposition to severe disease, and even head off medical calamity.

Lastly, there is the horrifying prospect of human cloning. Of course, cloning is ethically abhorrent. But I believe the era of cloning is upon us. And I can well understand how families with disabled or dying children could emotionally contemplate the creation of a clone. I have wondered myself often what Hillary's potential might have been, if she had not been struck down by a devastation invasion to her brain. Why not create Hillary II and find out?

Hillary's story is exceptional and dramatic. Her case has a reasonably happy ending. With her transplant, she is physically stable and healthy now. She has a family that loves her with all their heart. She has a wide circle of admirers who understand all she has suffered and who admire her determination and strength. But all cases of mental retardation and disability are

exceptional and dramatic. They all matter. In the United States alone, it is estimated that over 14 million people suffer from some sort of disability or mental retardation. Each of those individuals must have a team of family and professionals to care for them, and so the statistic is far higher than 14 million for those who are affected.

Disability remains the last frontier of civil rights. The question I was often asked, « How should the culture change in its attitude toward this community? » is a good one. For that very attitude defines the culture as humane or exclusivist. A geneticist once said to me, medicine 40 years from now, will be practiced very differently. She made her statement with pride and anticipation. And how would that affect the care of a child like Hillary, I asked her. A child like Hillary, she answered, would probably not be born.

That would be a tragedy, for the world would be poorer for it. Ultimately, the handicapped play a fundamental role in society. They can bring out the very best in a society and in an individual... and they can bring out the very worst. They define who and what we are.